CREATING PROGRAMS

CHAPTER 1:

Establishing Services

From the early years of the HIV pandemic, clinicians and program planners have recognized that HIV can exact an enormous toll on an individual's emotional health. Over the years, some AIDS service organizations (ASOs) and community-based organizations (CBOs) have tried to make mental health a service priority. However, since most of these organizations lack the necessary resources to meet the mental health needs of their clients, mental health services largely have been restricted to providing referrals to other community programs (e.g., community mental health centers) or offering limited on-site counseling for people living with or affected by HIV.

One of the lessons learned by the 11 sites that participated in the Demonstration Program was that programs interested in serving HIV-infected and -affected individuals need to augment their traditional mental health approaches with a biopsychosocial perspective. They also need to be responsive to persons who are hard-to-reach and have multiple service needs. This chapter presents steps for programs to consider and pursue in establishing services to address the HIV-specific mental health needs of their communities.

DETERMINING THE NEED FOR SERVICES

The types of services offered by a program should encompass the range of service alternatives required to meet the needs of the program's target population. Program planners and clinicians should recognize the need for mental health services when clients are not adhering to treatment, having interpersonal difficulties with medical service providers, missing appointments, or presenting with indicators of depression or anxiety. There are other indicators that can help administrators and clinicians determine what types of services should be provided. For example, changes in the demographics of persons affected by HIV underscore the need for "refined" or "different" services.

The first step in establishing services is to determine the need for HIV-specific mental health services. This may be done through:

- **Holding focus groups**. Invite the sharing of ideas and experiences by people living with or affected by HIV, medical providers, substance abuse treatment providers, mental health providers, program planners from ASOs and CBOs, and other local experts.

- **Seeking client input**. Set up suggestion boxes at the facilities where HIV-positive clients go for services. Periodically ask clients to fill out surveys. Invite persons living with HIV to participate on an advisory group. In addition to asking them to articulate their service needs, these venues provide an opportunity to gather information on service utilization patterns, program evaluations from a client perspective, and other information that can provide insight into how services can be improved and enhanced. Throughout these processes, program administrators and staff should keep an open mind. It may appear that the services being offered by a particular program are effective and operating in a smooth fashion, but some clients served by a program may not feel the same way. Program administrators and staff should be receptive to new ideas and consider all suggestions carefully and thoughtfully.

- **Conducting a needs assessment**. It may be wise to conduct a formal evaluation of service needs, to review recently published literature on needs assessments conducted with a similar population, and to distribute the needs assessment to key members in the community. A needs assessment will likely uncover unmet service needs in the community, as well as identify organizations and agencies that may be interested in collaborating in the establishment of HIV-specific mental health services.

- **Observing trends**. Program staff should continue to monitor local epidemiological data, as well as data from other areas that are ethnically, geographically, or socioeconomically similar for emerging trends in service needs and utilization patterns.

- **Listening to anecdotal information**. Service providers who work with HIV-infected and -affected individuals often talk in loose terms about the number of "mental health," "psychological," "family-related," or "depression/anxiety" complaints presented by clients. This type of anecdotal information may be useful in determining specific service needs that are not being addressed.

DESIGNING A RESPONSIVE PROGRAM

Once specific population needs are identified and documented, program planners and service providers can begin developing an action plan designed to meet the needs of a specifically defined target population or geographic service area. An action plan should identify how the program can address unmet needs. Designing a program and determining the feasibility of actually providing services happens almost simultaneously. (See the following section on "Determining Feasibility" in this chapter). Figure 5 presents examples of unmet mental health needs and possible treatment models/services.

Figure 5
Matching Client Services with the Target Population

Population/Unmet Need	Treatment Model/Services
Single mothers in advanced stages of HIV	Permanency planning Intensive case management Individual counseling in the home
Injection drug users	Traditional case management Relapse prevention Methadone maintenance Harm reduction Detoxification
Clients in advanced stages of HIV infection	Neurologic and psychiatric services Family education Support groups Psychiatric hospitalization case management Pastoral care Home services Telephone contacts
HIV testing	Individual counseling Case management Risk reduction services (psychotherapy and counseling)
Marginalized populations	Support groups Intensive case management Advocacy
Homeless	Aggressive outreach Field visits
HIV-infected women	Child care Parenting support/education groups Individual counseling
HIV-affected children	Family counseling and education

SELECTING THE SERVICE MODEL

In addition to considering the needs of the target population, program planners need to consider what the most appropriate services are and where they will be located within the existing service delivery model. Each of the 11 Demonstration sites devised a service model that was based on local needs, the capacity for community linkages, and funding allocations. Although each site provided a unique constellation of services, the mental health service delivery approaches fell into three broad categories:

Service Delivery Approaches Used in the Demonstration:

Traditional services with psychiatric evaluations, psychotherapy, and psychopharmacological management

Traditional services that integrated proactive community outreach and case management

Psychosocial rehabilitation and support services as the primary treatment modality

- Traditional mental health service models that offered psychiatric evaluations, psychotherapy, and psychopharmacological management (Atlanta, Chicago, Los Angeles, New York, Richmond, San Francisco, and San Juan). While each of these projects implemented similar service models, there was significant diversity in the populations served. For example, the Special Needs Clinic, located at Presbyterian Hospital in New York, primarily served children and families. Walden House in San Francisco served a predominantly substance using population. The Puerto Rico HIV/AIDS Mental Health Services Demonstration Project served a Latino population. The other projects implemented a traditional mental health service model that served large numbers of ethnic minorities, women, substance abusers, persons with severe mental illness, homeless individuals, men who have sex with men, and a few transgendered individuals. This diverse range of clients provided an opportunity to test the effectiveness of the traditional mental health service model across different target populations.

- **Traditional mental health service models that integrated proactive community outreach and case management** (Alexandria and Elizabeth). Both of these projects served typically hard-to-reach populations. For example, the Alexandria Mental Health HIV/AIDS Project focused on people with serious mental illness and substance use disorders, as well as homeless and incarcerated individuals. Kinship Connection in Elizabeth, New Jersey, identified women with HIV, their affected children and caregivers, and their reconfigured families as its target population. Given the composition of the target populations, these projects provided an excellent opportunity to identify effective ways to integrate assertive community outreach and case management into a traditional mental health service model.

- **Psychosocial rehabilitation and support services as the primary treatment modality** (Omaha and Philadelphia). The Harambee Project in Omaha targeted a diverse range of African Americans, including homeless individuals, women, injection drug users, and men who have sex with men. Consequently, the Harambee model emphasized group support and culturally relevant services as the primary means of treatment. Similarly, the Community Living Room in Philadelphia, which served an ethnically and socially diverse inner-city population, implemented a psychosocial rehabilitation model that emphasized peer support, social and support networks, education and empowerment, and helping clients acquire the knowledge and skills they need to live independently in the community.

A critical factor influencing the treatment approach for HIV-specific mental health service models is the location of services. The sites represented in the Demonstration Program reflect the creativity required to successfully match service delivery with client needs. Examples of site locations for HIV-specific mental health service models include:

- **Models co-located with HIV primary care facilities** (Atlanta, Chicago, Los Angeles, New York, Richmond, and San Juan). These projects typically focused on integrating mental health and HIV primary medical care to the greatest extent possible. For example, Atlanta's Center for HIV/AIDS Mental Health Services and the Los Angeles SPECTRUM Project created consortia of academic, state, and community-based ASOs to coordinate mental health services for people living with HIV throughout Atlanta and South Central Los Angeles. Chicago's HIV Health and Psychological Support Project replicated an integrated model of primary medical and mental health care at three community-based health centers, while the Mini Mental Health Center at the Medical College of Virginia in Richmond provided services in a university-based medical setting.

- **Models co-located with general mental health treatment facilities** (Alexandria and Philadelphia). The Alexandria project, an outpatient program within a community mental health center, provided traditional mental health treatment along with community outreach and close coordination with the city health clinic. Mental health and intensive case management services were offered in client homes, shelters, jails, and in the African American church. The Philadelphia project is a satellite program of a comprehensive community mental health center.

- **Models co-located with residential substance abuse treatment facilities** (San Francisco). The Walden House program in San Francisco provided mental health services for people with HIV in a structured substance abuse treatment setting. Depending on the client's needs, he/she had access to mental health counseling, substance abuse treatment, HIV counseling, housing, financial and legal assistance, medical treatment, education services, and vocational training.

- **Models that are free-standing in the community** (Elizabeth and Omaha). These two projects were unique in that they operated as their own entities within their respective communities and were not closely affiliated with a larger community organization or service program.

While factors such as funding and existing linkages within one's health care system are practical considerations guiding the approach and location of service models, one of the key lessons learned as a result of the Demonstration Program was the role of support structures. Developing or participating on existing advisory boards, networks, and consortia can put program staff in touch with others who may have confronted similar issues in the past and who can provide technical assistance on how to develop workable and effective solutions to unexpected and unanticipated challenges. Some of the support structures found to be helpful include:

...put program staff in touch with others...

- **Consumer Advisory Boards**. Typically comprised of clients, their significant others, and interested service providers, consumer advisory boards can provide program planners with the benefits of consumer input and perspectives on developing, monitoring, and improving service delivery. Meetings should be held regularly, and specific agendas should be established for each meeting. Program managers, administrators, clinicians, and other staff who keep an open mind when working with a consumer advisory board can gain valuable insight and ideas for achieving their program goals.

- **Collaborative Networks**. A collaborative network is composed of a series of formal or informal relationships among service providers and organizations with the purpose of furthering programmatic goals and objectives, and improving overall client care. Among other features, collaborative networks can also ensure that services are available and accessible to clients. (See Chapter 2 on Collaborative Networks.)

- **Consortia**. Similar to networks, a consortia usually evolves out of formal agreements among service providers from different organizations who pledge to coordinate services. The difference between consortia and networks, however, is that members of a consortia also share and distribute funding resources. Many HIV-specific consortia were established in response to the requirements of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. In fact, most states and territories have at least one consortia in place. These consortia have administrative structures and procedures designed to increase client access to care and to equitably distribute funding among participating organizations. As a general rule, any "new" service would benefit from establishing a formal linkage with local consortia.

DETERMINING THE FEASIBILITY OF THE PROGRAM

Once service needs are concretely identified and possible service model solutions are drafted, program planners can consider the feasibility of offering HIV-specific mental health services. Numerous questions may arise regarding such issues as implementation, cost, staffing, and the political environment. Some of the most critical areas identified by the Demonstration Program are described below.

Existing organization. Adding a new, HIV-specific mental health program to an existing administrative structure can have both advantages and disadvantages. Personnel at all levels of an organization may be affected by the challenge of changing an existing service delivery structure. Program administrators may want to conduct a careful analysis of these pros and cons prior to proposing such a dramatic change in an organization's scope of services. Some key areas to consider regarding the organizational factors are:

- Historical responses to change. How has the organization changed to adapt to client needs in the past? Do staff or administrators view change negatively? Is organizational change usually a random occurrence, causing anxiety among staff and clients? Or is change a routine and ongoing process? It is important to define change as a positive action and to set an agenda for regular review and revision of organizational and programmatic efforts. This approach can help staff anticipate and prepare for the possible outcomes of change.

- Mission and vision. Does the organization have a clearly stated and clearly articulated mission? Does the program itself have a realistic vision for the kind of positive impact it can have on the lives of clients? Do existing staff, administrators, board members, and other relevant personnel support the program's vision and share a commitment to making the vision a reality? If the answer to any of these questions is "no," then the program's ability to meet the needs of its clients in a unified fashion may be severely compromised.

- Philosophical approach to working with clients. Too often, health care professionals assume that everyone in the field is equally committed to the general goal of doing what is best for the client. In reality, however, there are many ways to serve clients effectively, and different professionals may have different values or perspectives when it comes to delivering services.

- Flexibility around established procedures. Will staff in the new program be required to complete organizational paperwork that does not pertain to their work with clients? What are the costs to the organization if established procedures are not undertaken by staff? It is important to weigh the costs and benefits of requiring program staff to perform established procedures, especially since they will have the additional task of serving HIV-infected and -affected individuals that other organizational staff may not have.

Funding (short-term and long-term). Funding for services is the fuel that enables a program to run efficiently and effectively. Far too often, service planners underestimate the costs associated with providing certain services. To avoid this problem, program staff should carefully consider the range of services that are essential to meet client needs, the number and type of service providers available to the program, necessary equipment and materials, overhead, and indirect costs. An old-fashioned and carefully crafted budget is still the best way to determine if the available financial resources are sufficient to meet the program's service goals.

This budget may include:

- Sources of reimbursement, such as client payment for services, Medicare and Medicaid, and private health insurance
- Outside funding sources, such as federal, state, county and city governments, private foundations, charitable organizations, and United Way funds
- Ryan White CARE Act funding
- In-kind contributions, such as staff, office space, utilities, furniture, or equipment

Once funding sources are identified, program planners and administrators can become better positioned to determine the economic feasibility of providing the range of services that were originally planned.

Sources of reimbursement:

Outside funding sources

Ryan White CARE Act

In-kind contributions

Political climate. The level of support for a new HIV-mental health program may be closely tied to, or dependent upon, the current political climate in which the program will operate. Some program efforts (e.g., needle exchange or condom distribution programs) may not receive support from certain parts of the community. Many political leaders have different points of view about funding priorities (e.g., whether limited resources should be allocated to local, county, or state levels). Programs that opt to provide a certain service may find themselves in competition for funds with other organizations providing similar services. Administrators will want to discuss plans for new services with representatives of other community or state organizations to determine if new services will be supported and embraced by state and local political leaders.

IMPLEMENTING THE PROGRAM

After funding has been secured, the organizational factors have been considered and managed, and the program design has been established, it is time to put the program into action. Once the program begins the implementation phase, staff may find that there is a greater demand for services than the program is able to provide. To manage funding, human, and service resources effectively, program planners and administrators will have to establish priorities.

Triage plan. Most programs would like to provide services to everyone who needs them, but trying to meet everyone's needs will probably result in depleting already limited resources sooner than expected. Before things get to this point, it is wise to establish a detailed, yet flexible, triage procedure that outlines specific inclusion and exclusion criteria.

Space. The provision of mental health services requires a safe, confidential atmosphere. Offices in which clients will receive services need to be enclosed to prevent others from eavesdropping on conversations between the service provider and the client. In designing or planning the use of office space, reception areas, and waiting rooms, consideration needs to be given to ensuring confidentiality, equal treatment, and handicapped access.

Staff. The recruitment of trained and motivated staff is critical to establishing new services. Administrators need to determine if an adequate supply of human resources is already available or if additional staff need to be recruited. (For additional discussion about staffing issues, see Chapter 3.)

Service Intensity. Different persons not only need different services, but they also need varying "doses" of services. Too many agencies establish a service model that expects the services offered to be sufficient for all clients who walk through the door. The fact is that no single organization can provide all the possible combinations of services needed by persons living with HIV. Programs need to consider the following questions:

- *Will the program provide support services in addition to mental health services?*
- *To what extent is the program able to meet the transportation needs of clients, such as giving clients bus tickets or taxi vouchers, so they can attend their sessions and other health-related appointments?*
- *What kind of formal and informal linkages will the program have with other providers who serve people living with or affected by HIV?*

Resources for staff. In addition to having an enclosed, private space to meet with clients, staff may need access to password-secured computers and locked file cabinets for storing confidential materials. Staff who conduct work outside of an office setting (e.g., outreach workers) may need pagers or cellular telephones to maintain contact with clients and other service providers. If a program intends to provide transportation, agency cars or vans are needed.

...service, training, and evaluation...

Publicity and marketing. Existing service organizations cannot assume that clients will simply hear about new services and request them. Services need to be marketed to clients and other service providers. Service providers and potential clients need to know what mental health services are and how clients can benefit from them.

Clients and service providers also need to be educated about the warning signs of diagnosable and treatable mental disorders. For example, many individuals living with or affected by HIV often may feel "sad," not realizing that they may be experiencing a depressive disorder. How a program informs and educates potential clients and referral sources about mental health issues and new services is a key challenge. Inviting service providers and potential clients to educational workshops that explain what mental health services are and how they can help people living with or affected by HIV is one suggestion. Publicizing services can be done by handing out flyers at a local grocery store or sending a one-page description of the program to other service providers in the community.

Staff training. Program administrators have to provide awareness training to all personnel within their facility to make sure they understand what the newly established services are, when a potential client should be referred for mental health services, and what the benefits are for the clients. In addition, existing staff need to know how these new services may change the scope of their duties. Staff may express anxiety or anger about taking on new responsibilities, or they may fear that they will lose their jobs when new (and perhaps more experienced) staff are hired. (See Chapter 3 on Staffing.)

Policy and procedures manual. It may be useful and beneficial to develop a "Policy and Procedures Manual" that can be modified as new situations arise. The manual may include up-to-date copies of all organizational and program forms, such as intakes and assessments. New procedures can be reviewed frequently by appropriate staff early in the program implementation process.

Program evaluation. An important lesson learned from the Demonstration Program was that the evaluation of services should be considered early on in the program development process. Program administrators need to set aside funding for evaluation and for educating staff about the importance of evaluation in informing program decisions and policies. (For a more comprehensive presentation of these issues, see Chapter 14 on Evaluation.)

SUSTAINING THE PROGRAM

Sustaining an HIV-specific mental health program is about much more than funding. It is also about recruiting and retaining staff; providing staff training; engaging and retaining clients; coordinating services within the network of available services; keeping providers informed of emerging clinical issues and procedural changes; and preventing or reducing provider burnout. These program development issues are discussed in more detail later in the Practical Guide and are critical to the program implementation process.